



***Review of Policy Implementation
2012-2017***



***Time to Move On
From Congregated Settings:
A Strategy for Community Inclusion***



TRANSFORMING LIVES

Programme to Implement the Recommendations of the 'Value for Money and Policy Review of the Disability Services in Ireland'

1. Contents

1. CONTENTS	2
2. ACKNOWLEDGEMENTS	3
3. INTRODUCTION	4
4. DISABILITY POLICY OVERVIEW	5
5. SUPPORTING THE POLICY IMPLEMENTATION	6
RESOURCE ISSUES	6
CAPITAL FUNDING TO SUPPORT THE IMPLEMENTATION OF THE POLICY	8
5.1.1 <i>Department of Housing Capital Funding</i>	8
5.1.2 <i>HSE Disability Capital Programme 2016-2021</i>	8
TRANSITIONAL FUNDING	8
6. CHANGES TO CONGREGATED SETTINGS PROFILE FOR PERIOD 2012- 2017	10
MOVEMENTS IN THE CONGREGATED SETTING POPULATION OVER PERIOD 2012-2017	10
ANALYSIS OF THE TREND IN THE NUMBER OF PEOPLE WHO TRANSITIONED 2012 - 2017	11
6.1.1 <i>Transitions in 2014</i>	12
6.1.2 <i>Transitions in 2015</i>	12
6.1.3 <i>Transitions in 2016</i>	12
6.1.4 <i>Transitions in 2017</i>	13
PROFILE OF PEOPLE WHO TRANSITIONED BETWEEN 2012-2017	14
INDIVIDUALS WHO PASSED AWAY 2012 TO 2017:	17
PEOPLE ADMITTED /READMITTED 2012 TO 2017:	17
CONGREGATED SETTINGS THAT HAVE CLOSED	18
7. TIME TO MOVE ON - A RESIDENT'S PERSPECTIVE	20
8. STATUS OF CONGREGATED SETTINGS AT END OF 2017	26
8.1 PROFILE OF RESIDENTS IN CONGREGATED SETTINGS ON 31/12/2017	26
9. LEARNING AND KEY MESSAGES TO DATE	32
SUCCESS FACTORS	32
9.1.1 <i>LEADERSHIP: Clear, supportive and driven leadership</i>	32
9.1.2 <i>KEEPING IT LOCAL: Supporting local decision making and local responses</i>	33
9.1.3 <i>COMMUNICATION: Prioritising and supporting meaningful engagement and communication.</i> ...	34
CHALLENGES	35
KEY CONSIDERATIONS GOING FORWARD	35
VIEWS FROM OTHER STAKEHOLDERS	37
9.1.4 <i>Health Information & Quality Authority (HIQA)</i>	37
9.1.5 <i>The "Moving In" Study: National Disability Authority</i>	38
10. THE CRITICAL NEXT STEPS	41
APPENDIX 1: STATISTICAL INFORMATION CHO TRANSITIONS 2012-2017	43
APPENDIX 2: STATISTICAL INFORMATION CHO RESIDENTS REMAINING 2017	45

2. Acknowledgements

Firstly, I would like to acknowledge the commitment and work of all those who have participated on the national groups and subgroups leading the implementation of *Time to Move on* since 2012. I also wish to acknowledge the support of the Transforming Lives Programme Manager and the Programme Sponsor whose guidance and oversight has ensured that the work of these groups has continued to effectively drive change.

I also wish to acknowledge the many stakeholders that have engaged with us to share their expertise provide valuable support and guide the work of the groups. This includes representatives and colleagues from the Department of Health, the Department of Housing, the Housing Agency, the National Disability Authority, the National Federation of Voluntary Bodies, the Disability Federation of Ireland, the Expert Working Group on Congregated Settings, the Irish Council for Social Housing, Inclusion Ireland and from across the HSE.

Over the last five years, the level of engagement and support that the project team have received directly from service providers has been invaluable in enabling us to gather robust data, visit sites, develop resources and share learning. These contributions have helped ensure that the on-going work of the national group and the HSE Disability team is targeted to bring about real change in the lives of people currently living in congregated settings.

I also wish to give a special mention to the residents themselves and their families, friends and supporters who are travelling on this significant journey with us. Their challenges, questions, ideas and support are critical and ensure that we can continue to shape our approach and strive to “do better” for every person.

Finally, I wish to acknowledge the staff working at all levels in organisations across the country whose leadership and resilience is supporting people to move to new homes in their communities. The ongoing commitment of these staff to the vision of *Time to Move on* is fundamental in bringing about meaningful and sustainable change that is enabling people “*to live ordinary lives in ordinary places*”.

Suzanne Moloney

Chair of Time to Move on Subgroup & HSE Project Lead

3. Introduction

This report has been drafted to provide an overview of the progress achieved so far in transitioning people from congregated settings to community based homes of their choice, in line with the *Time to Move on* policy.

The report gives an overview of the relevant disability policy, reform programme and implementation structure for the policy. It summarises the work being undertaken at a national level to drive the implementation of the policy. Statistical data relating to all those that transitioned over the period 2012 -2017 and the residents that remain living in the congregated settings at the end of 2017 is included.

A key feature of this report is the personal stories that have been included to capture the impact *Time to Move on* has had on individuals living with disabilities. In addition to this, the report identifies the key messages and the learning that has emerged from a range of sources, which continue to inform how we move forward with implementation.

Ultimately, the effectiveness of the policy will be determined by the positive impact it has on the lives of people with disabilities, captured through quality of life outcomes. In this regard, the views of the Health and Information Authority (HIQA) are noted as a critical stakeholder influencing the shape of residential services through regulation. A commentary from the National Disability Authority is included, with the initial findings from the *Moving In* study. This large study, under the Transforming Lives programme is examining the impact of moving to community based services through individual assessment processes pre and post transition.

The report concludes with an outline of the critical next steps required to continue driving the implementation of the policy, which will ensure all those living in congregated settings can be supported to live ordinary lives in ordinary places.

4. Disability Policy Overview

In June 2011 the report *Time to Move on from Congregated Settings – a Strategy for Community Inclusion* was published. This report identified that in 2008 approximately 4,000 individuals with disabilities lived in congregated type settings, defined as

“where ten or more people reside in a single living unit or are campus based”.

The report found that notwithstanding the commitment and initiative of dedicated staff and management, there were a significant number of people still experiencing institutional living conditions, where they lacked basic privacy and dignity, and lived their lives apart from any community and family. The report made 31 recommendations covering a wide range of issues and identifying a diverse group of stakeholders and responsible bodies.



Since 2014, the **Transforming Lives** Programme has driven the implementation of the recommendations of the Department of Health’s 2012 *Value for Money and Policy Review* report and national disability policies to deliver person-centred models of service. The *Time to Move on* Subgroup under Transforming Lives has responsibility for:

Implementing the initiatives which underpin and enable a new model for residential support in the mainstream community, where people with disabilities are supported to live ordinary lives in ordinary places.

This is a multi-stakeholder, cross-departmental group that drives the implementation of the policy and provides support and oversight at a national level.



5. Supporting the Policy Implementation

Since 2012 the implementation of the policy has been supported by and through a range of activities. The national *Time to Move on* subgroup under Transforming Lives and a small project team have lead and supported the implementation through:

- Data collection through the congregated setting master data set that provides comprehensive oversight of the activity and progress, enabling targeted support and informing resource allocation.
- The development of a suite of stand-alone resources for providers that includes guidance documents, planning templates, toolkits, mapping tools etc. Collectively these resources form the *Time to Move on* Implementation Framework and can be accessed on the dedicated webpage www.hse.ie/timetomoveon/
- Dedicated work streams – A number of small groups have been established comprised of key stakeholders and experts to focus on addressing particular issues that arise in relation to the policy. These are time limited groups with specific terms of reference and objectives.
- A series of learning events, information sessions and workshops hosted and/or supported by the project team.
- Significant and ongoing cross-departmental and cross-agency engagement to address cross-cutting issues.
- Location visits to engage with and support services directly.

Resource Issues

Comments in the original *Time to Move on* report suggested that the overall funding dedicated to residential services at that time, should be sufficient to support people in community based residential services, without the need for additional resources. This is often referred to as a “cost-neutral basis”. However there are a number of underlying caveats and dependencies that have worked against this premise. These include:

- Transitional and seed funding requirements
- The responsibility for the delivery of certain supports rests outside of the disability providers: housing, transport, primary care, social protection and local community support.
- The funding impact of public sector agreements on service reconfiguration plans
- The impact of the terms and conditions of employment held by workforce
- The existing allocation of resources and governance framework for services managed through service arrangements
- The lack of an evolved process to enable the transfer of funding and resources between providers, a “*money follows the patient*” approach or the widespread utilisation of personal budgets.

The original *Time to Move on* report recognised that there are cross-cutting issues that will require innovative and new approaches with the support of many stakeholders. An update on the current status of the report recommendations is included in the 2017 Annual Progress Report.

Since the original report was published, the potential to achieve significant change within the existing funding on a cost neutral basis has also been eroded due to:

- Reductions in core revenue funding through years of austerity measures
- An ongoing demand for new additional residential placements
- No additional revenue funding since 2008 for new or enhanced residential places
- Changing need of those receiving residential supports

However, it can be argued that the most critical factor impacting the capacity of the disability sector to reconfigure under *Time to Move on* within existing resources, has been the parallel issue of the quality and standard of the services being delivered. The *Time to Move on* report was developed over the period 2008-2011, several years before the introduction of the *National Standards for Residential Services for Children and Adults with Disabilities* and the commencement of regulation by the Health and Information Authority (HIQA) in late 2013. The *Time to Move on* report did not consider the impact of regulation across residential services.

On the ground regulation, turned a spotlight on deficits in the quality and standard of the services which necessarily became a significant cost driver across both congregated and community based residential services. Many providers now face increased capital and revenue costs in order to achieve compliance with the regulations and address the complex and at times urgent issues in relation to the quality and safety of services. At a national level, it has been necessary for additional revenue funding resources to be prioritised and allocated to address the deficits in some residential services, in order to ensure that people with disabilities are appropriately supported in a safe and compliant environment. Despite the financial challenges outlined and the welcome emphasis on the introduction of quality standards in residential services, progress has been made. HIQA have worked with providers and the HSE around registration and compliance issues to support the process of decongregation.

Capital Funding to support the implementation of the policy

5.1.1 Department of Housing Capital Funding

In line with the National Disability Strategy for People with Disabilities 2011-2016, there has been significant engagement between the government, statutory bodies, voluntary organisations and other agencies in relation to how the housing needs of people moving from congregated settings can be addressed.

Since 2014 a number of innovative projects have been funded through the housing sector to test and demonstrate the feasibility of different approaches in relation to the funding, design and configuration of housing for people with disabilities. Building on this, the Department of Housing committed funding in 2016 and 2017 under the Capital Assistance Scheme for the delivery of homes to support people transitioning from congregated settings. Over this period over €8.8million had been approved for properties to support those moving.

5.1.2 HSE Disability Capital Programme 2016-2021

In 2016 the Department of Health made a commitment to a Disability Capital Programme of €100 million dedicated to the provision of accommodation for those individuals moving from congregated settings to homes within the community over the six year period 2016-2021.

A total of €40 million was allocated during 2016 - 2017, specifically targeted and aligned to ensure that appropriate homes will be secured for the people engaged and planning their transition to the community from the settings prioritised for decongregation. At the end of 2017 there were 89 properties completed or being progressed so far under this funding. Collectively these 89 properties will provide a home for 332 people with the average costs currently running at €132,500 per person and €494,000 per property (houses vary from single person arrangements to house for 4 people), including full fit out and furnishing.

Transitional Funding

Established in 2015 the Service Reform Fund (SRF) supports the implementation of reform in the Disability and Mental Health Services by providing funding to meet the costs of migrating to a person-centred model of services and supports, in line with government policy.

Underpinned by a Memorandum of Understanding between the Department of Health, Atlantic Philanthropies and the HSE, projects under the SRF are approved by a multi-stakeholder group. The ongoing support and oversight of the disability projects is managed by the Genio Trust and the HSE who work in close collaboration.

In 2016 ten congregated setting sites were prioritised for the initial stream of SRF funding to progress their plans in line with the principles of person centeredness and to achieve an agreed target level of transitions. By the end of 2017, significant progress had been achieved with 119 transitions completed across the priority sites although the rate of change varied from site to site. Overall there continues to be a momentum gathering in these settings to achieve transformational and sustainable change.

6. *Changes to Congregated Settings profile for period 2012-2017*

In 2013 a master data set was introduced to collect detailed data on the population that had been resident in congregated settings since the policy was implemented at the start of 2012. This was the first data update since the original report data was collected in 2009. The master data set has been updated annually and a body of work has been undertaken to merge and validate the data on all the movements since 2012. The information presented below represents the key findings from this exercise.

Movements in the congregated setting population over period 2012-2017

The original report identified that 4,099 people were living in congregated settings in 2009. The data indicates that by 2012 there were 3,401 people still living in these settings. This figure fell to 2,370 by the end of 2017, which is 1,021 fewer people or a 30.1 % decrease in the total congregated setting population from 2012-2017. This takes account of all the movements in the population including deaths, emergency admissions and other discharges and transfers as well as those that transitioned to the community. In Table 1 below, information is given on the movements in the congregated setting population over the period 2012 - 2017. This shows that since the policy commenced 661 people have been supported to transition, 592 people have passed away and 222 were admitted. The trends in these movements are discussed in further detail below.

Table 1: Movements in the congregated settings population from 2012 to 2017	
No. of residents in 2012	3,401
No. of people who transitioned	661
No. of people who passed away	592
No. of people admitted or re-admitted	222
No. of residents at end of 2017	2,370

Analysis of the Trend in the Number of People who Transitioned 2012 - 2017

Between 2012 and 2017 a total of 661 people completed their transition to the community. In Chart 1 below, the number of transitions that were achieved in each calendar year is identified.

Chart 1: Number of transitions completed between 2012 – 2017



There has been a considerable swing in the number of transitions achieved year on year, with 2015 being the most prolific year with 150 transitions completed and 2014 yielding the lowest number with 67 moves to the community. Looking at the annual numbers in isolation provides little clarity as to why there have been swings in the activity. However, by looking at the profile of individuals moved, the locations and services from which they moved and identifying the resources available each year to support transitioning, it is possible to understand and explain the fluctuations in activity.

The vast majority of the early gains made in transitioning people to the community, came about in services that made an intentional decision to decongregate particular locations. In some settings this was a positive strategic decision made at Board or senior management level to implement a community living policy. In other settings, transitions were progressed in order to address other issues and challenges that included difficulties arising from institutional practises and inappropriate accommodation.

6.1.1 Transitions in 2014

The drop in transition activity during 2014 follows the commencement of the Health and Information Authority (HIQA) regulation of disability residential services in November 2013. Across the sector services diverted their attention and resources towards achieving regulatory compliance. As a result, the momentum of transitioning people to the community was interrupted in many cases. During 2014 there was also a change in the national structure driving the policy implementation when the National *Time to Move on* Implementation Group was stood down midway through 2014 and reconstituted under the Transforming Lives Programme at the end of 2014. Without national direction and oversight, there was no driving force for policy implementation other than local commitment for a period of time.

6.1.2 Transitions in 2015

In 2015 supported by the prioritisation in the HSE National Service Plan and the renewed focus on driving implementation from the *Time to Move on* subgroup there was an increase in transitions. Many of those that transitioned in 2015 were from service providers often referred to as the “early adopters”, which are the locations that had already shown a commitment towards person centred models of service and had made substantial progress in moving into the community, even before the policy was adopted. As no additional revenue resources were allocated nationally, these transitions were completed by services that had the capacity to reconfigure resources and/ or access to additional funding from other sources, which in some cases included securing support through local negotiation. Importantly, 2015 was the last year in which a substantial number of transitions were completed with no additional resources.

6.1.3 Transitions in 2016

The drop in activity that occurred in 2016 indicates that many services, including the early adopters, no longer had the capacity to support individuals to transition to the community without additional resources. Whilst significant capital and revenue resources (via SRF) were made available to support transitions in 2016, this funding was targeted towards a number of priority sites¹, which were only beginning to engage with the process of decongregation from a “standing start”. As a result many of the transitions planned in

¹ The priority sites are specific locations where there are serious concerns around the quality and safety of the service and significant non-compliance issues.

2016 were not completed until 2017. Other issues encountered included the length of time required to find, secure and make-ready the new homes. Time was also required to work with residents, their families and friends and staff to support each person to move to the community at their own pace.

6.1.4 Transitions in 2017

In 2017 there was an upturn in activity and an increase in the numbers transitioning. This was anticipated, as it was a result of the work and investment that began in 2016. There were still some delays in 2017 that arose where the progress on specific housing projects was slower than expected. In a small number of cases there were also difficulties with staffing arrangements that led to small delays so that the transitions were completed in early 2018.

The experience from the development of homes under the HSE Capital Disability Programme shows that on average it has taken 12 months from the time a house is identified until the residents move in. This is much longer than the average time required to move home which is between 8- 21 weeks (www.comparemymove.com). Impacting on the delivery of these homes is the time needed for additional tasks which can include: developing works specification; going to tender and awarding contracts for works; completion of works; completion of all necessary registration and certification arrangements, completing the fit-out and furnishing and supporting the resident to transition.

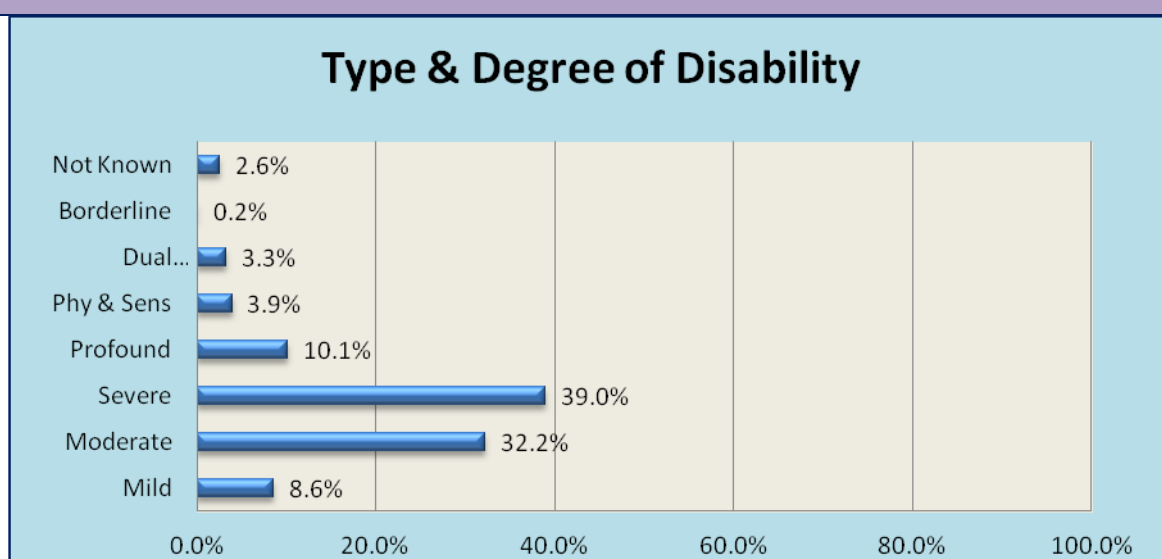
Going forward, there is a new momentum and commitment to implementing the policy in most settings that should enable steady progress to be made in line with activity targets for the coming years within the available resources. The ongoing allocation of funding under the HSE Disability Capital Programme 2016-2021, through the Capital Assistance Scheme and through the Service Reform Fund will be critical to sustaining this progress.

Profile of people who transitioned between 2012-2017

Some basic profile data has been collated for those who transitioned between 2012 and 2017. In the tables below statistical data is provided in relation to type and degree of disability, the level of support needs and age profile. Although the data has improved year on year, there were a number of data gaps, which results in an “unknown” classification in most charts.

The Type and Degree of Disability of the people who transitioned during 2012-2017 is captured in Chart 2 below. Amongst the 655 people who transitioned, almost 49% (325) of the people were identified as having a severe or profound intellectual disability. A further 32% (213) had a moderate level of intellectual disability and fewer than 9% were recorded as having a mild disability.

Chart 2: Type & degree of disability of people who transitioned between 2012 – 2017



Interestingly, these percentages are similar to the breakdown of the population by degree of disability recorded in the original report. This indicates that the type and degree of disability has not been a significant factor in determining who will transition and that there is no evidence of a bias towards supporting a particular group to move to the community.

In Chart 3 below details are given on the levels of support of the people who transitioned during this period. The data indicates that high levels of support were provided to over 58%

(385 people), with moderate levels of support to 21% (138 people) and intensive support provided to 7.2% of people. This broadly mirrors the statistical information on the type and degree of disability identified for those who transitioned, indicating that at the time of transition there is a strong correlation between the degree of disability and support need.

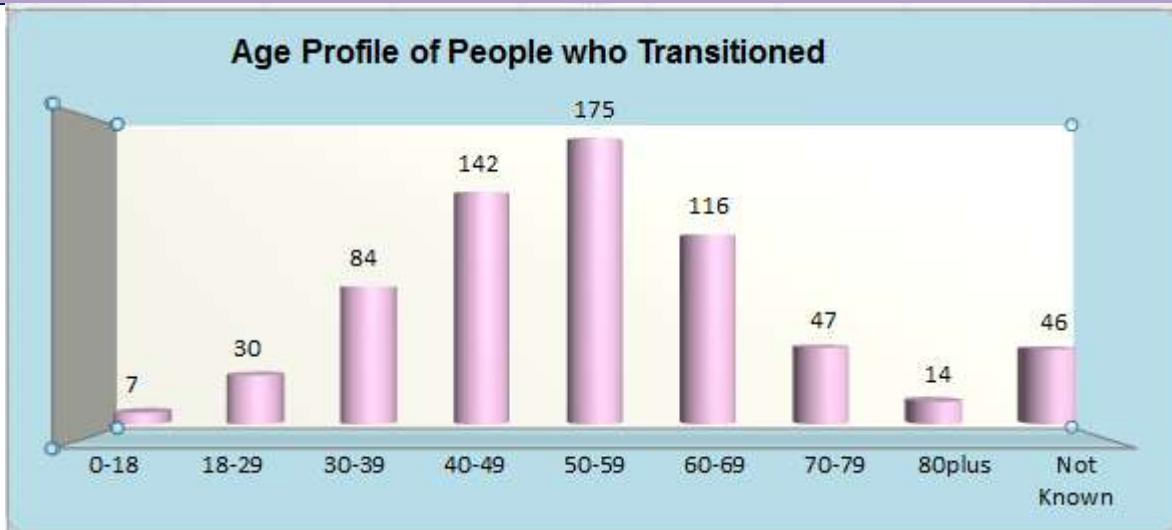
Chart 3: Level of support to people who transitioned between 2012 – 2017



Unfortunately there has been no information collated to date to examine how the configuration of resources and supports might have changed over time as people settle into the community and their needs change. Anecdotally, there are cases reported where support levels have decreased, ranging from moderately small changes through to significant reductions in support. There are also examples of increased supports being put in place. Any analysis of the change in support needs will need to be carefully measured against the outcomes achieved for the individuals. Ultimately to enable people to live an ordinary life of their choice, the model of support will differ significantly to the traditional congregated setting service provision and include supports from the community.

Chart 4 below, gives an overview of the age profile of all those who transitioned during 2012-2017. This shows that 48% (317) were aged between 40 and 60 year olds and a further 18% (116 people) were aged between 60 and 69 years old at the time of transition. Again, as with the discussion points around the level of disability for those who transitioned, these percentages are similar to the age profile recorded in the original report in 2009. This indicates again that there has not been a bias towards supporting a particular group of residents based on their age.

Chart 4: Age profile of people who transitioned between 2012 - 2017



Finally, whilst there is not a complete suite of information in relation to the 661 people who have transitioned, the data shows that 59 % (390 people) who transitioned from congregated settings had been resident in an institution for over 20 years prior to their move to the community and a further 14.7% (97 people) had lived in a congregated setting for between 11 and 20 years before they transitioned.

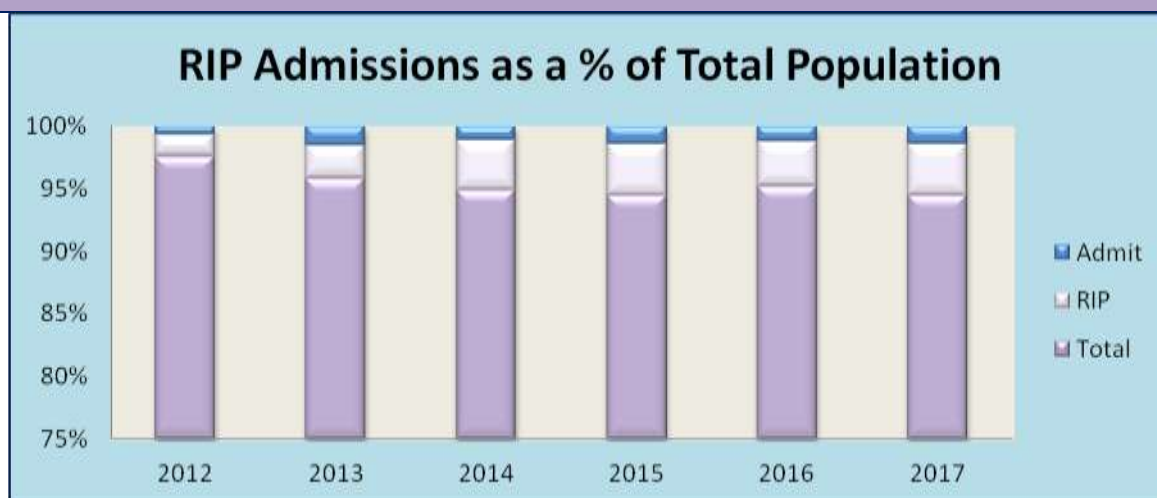
The following tables are available by Community Health Organisation in Appendix 1:

- Age profile of residents that transitioned from 2012 to 2017
- Level of disability of the people that transitioned from 2012 to 2017
- Level of support needs of the people that transitioned from 2012 to 2017
- Length of stay in congregated setting prior to transition

Individuals who passed away 2012 to 2017:

During the period 2012-2017, a total of 592 people residing in congregated settings passed away. The number of residents who pass away each year has remained relatively constant and equates to approximately 4% of the total number of people living in congregated settings in any year. In Chart 5 below, the overall population at the end of each year is compared to the rate of admissions and deaths that occurred in the preceding 12 months.

Chart 5: RIPs and Admissions shown as a percentage of total population



People admitted /readmitted 2012 to 2017:

During the period there were 222 people who were admitted / readmitted to a congregated setting. There were 48 people admitted /readmitted in 2013 which was the highest annual admission/readmission rate during the period. This pre-dated the Transforming Lives programme which renewed the focus on implementing the policy and has continued to advocate for the number of admissions to be minimised to the greatest extent possible, but has stopped short of issuing a direction to close all services to admissions. This position recognises that at times, a short-term placement in a registered bed in a congregated setting may be the only option available in response to a crisis or emergency situation.

Since 2014, the number of people being admitted /readmitted annually is less than 1.5% of the total numbers resident in congregated settings. Looking at the detail, in particular over the last 3 years, the main reasons for admission/readmission continue to be changing health needs and emergency /crisis admissions.

Congregated Settings that have closed

The list of settings that have completely closed since 2012 remains relatively small, even though over 600 people have transitioned to community and there has been a decrease of over 1,000 people living in congregated settings. In total since 2009, 12 centres have closed entirely:

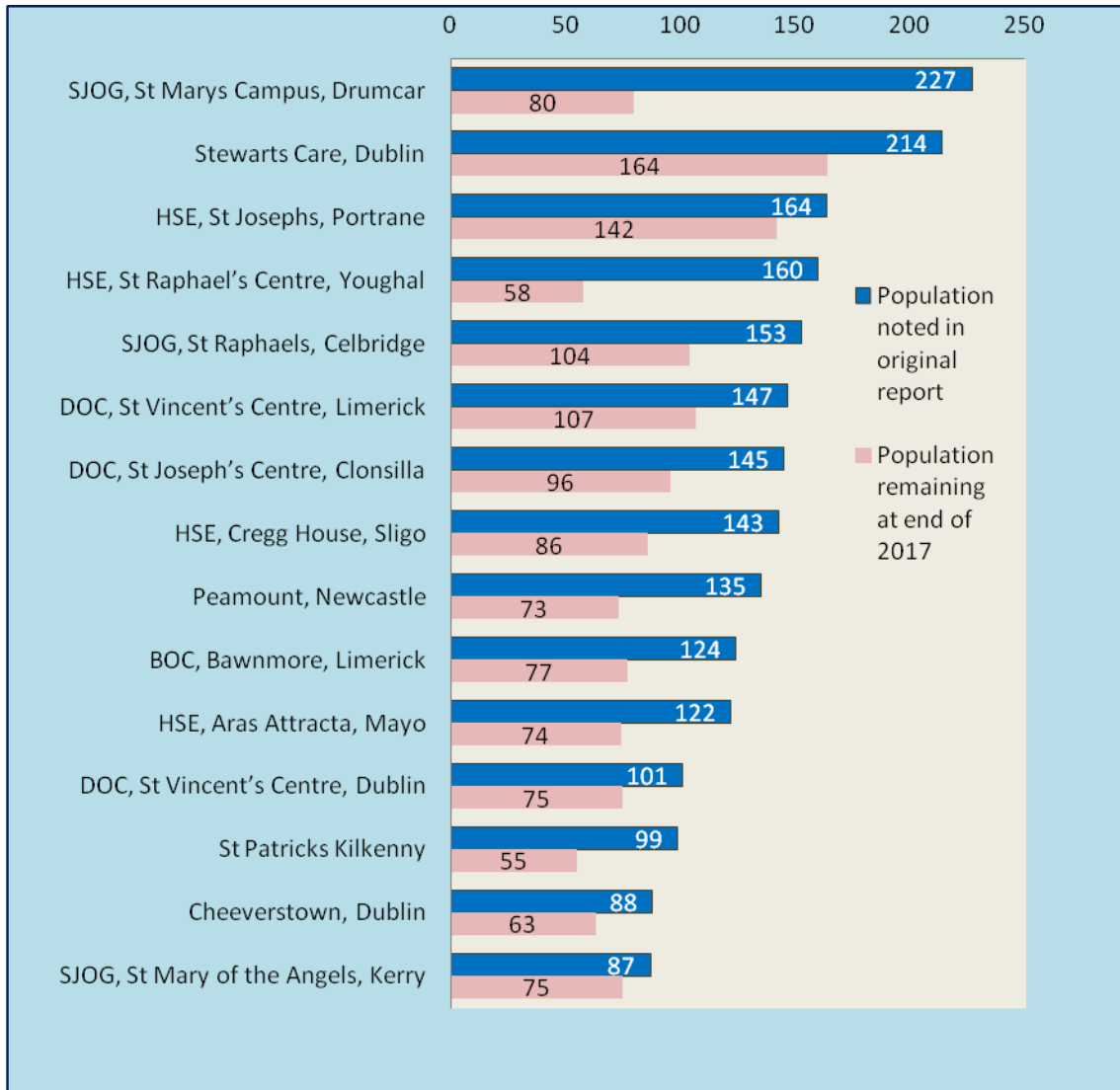
- Cheshire Ireland, Barrett Home, Dublin (pre 2012)
- Brothers of Charity Renmore House, (pre 2012)
- Daughters of Charity, St Teresa's, Temple Hill Dublin (pre 2012)
- HSE, Alvernia House, Portlaoise (2012)
- HSE, Lough Sheever Centre, Mullingar (2012)
- HSE Clogher House, Rooskey, Monaghan (2013)
- St. Paul's, Dublin (2013)
- HSE, St. Peter's Centre, Castlepollard, Co. Westmeath (2015)
- Brothers of Charity, Kilcornan Centre, Galway (2015)
- HSE Good Counsel, Ballyboden, Dublin (2015)
- Grove House, Cork City (2016)
- Cheshire Ireland, Richmond Home, Co. Dublin (2017)

This reflects that many of the congregated settings are large services comprised of multiple smaller units on a campus. At the end of 2017 there were 58 congregated centres made up of 312 houses/units. The full list of all congregated settings remaining at the end of 2017 by CHO Area is included in the 2017 Annual Progress Report available on the webpage www.hse.ie/timetomoveon/.

As individual residents are being supported to move to the community, the reduction in the numbers remaining on each campus is being actively managed. This ensures that the people remaining, some of whom may continue to live in these locations for several more years, can be more appropriately accommodated and supported on site. In some cases, there is a reconfiguration of support and living accommodation to better meet individual needs. This might relate to improving privacy, addressing safe-guarding issues or providing an opportunity for people to live with friends of their choice, often in preparation for moving to the community together. In other cases, particular units or areas within a campus will be prioritised for closure whilst others remain open.

A review of the population numbers in the 15 largest settings from 2009 to 2017 is given in Chart 6 below. This shows the significant progress made in reducing the numbers in these particular locations, even though they still remain open at this point.

Chart 6: Resident population in the 15 largest settings in 2009 and 2017



7. Time to Move on - A resident's perspective

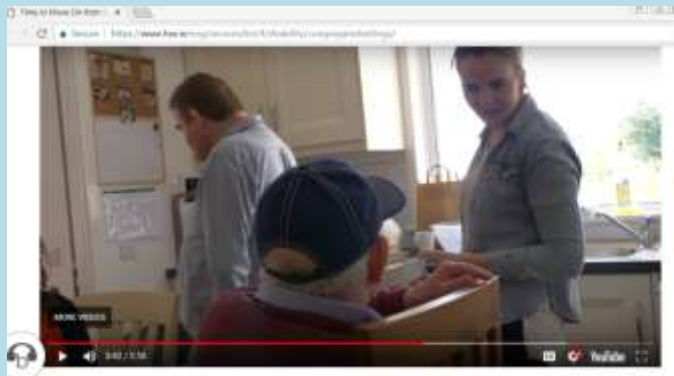
The Transforming Lives programme is focussed on enabling people with disabilities to achieve their full potential and live ordinary lives in ordinary places, as independently as possible. A fundamental step to achieving this is to ensure that the voices of service users and their families are heard and that they are fully involved in planning and improving services to meet their needs.

It is important to reflect that behind the numbers of people transitioned are the individuals who each have their own personal experience of transitioning. Each person's perspective will be different on how they have been supported to transition to homes in ordinary communities and are now being supported to live full, inclusive lives at the heart of their family, community and society.

Three of these personal stories are featured below:

"The Three Gentleman of Youghal"

At the end of 2017 a film was taken to capture the day to day life of Jerry, Sean and Finbarr in their new home and shows how the transition to community living with the support they need, demonstrates that this kind of move can literally 'transform lives'. The video can be seen on <https://www.hse.ie/etimetomoveon/>



'Surpassing anyone's hopes', 'excelling', 'a joy to watch', 'endless potential', 'big positive change', 'a lot happier'. This is what staff and family members have to say about some of the former residents of St Raphael's Residential Centre for people with intellectual disabilities in Youghal, Co. Cork who have moved from the centre and now live in their own homes in the tranquil seaside town. One mother says' "Since Sean moved here I have seen great changes in him – he's a lot happier in himself... He is completely changed. It's brilliant," she smiles.

“Rosaleen in conversation over tea”

When people started moving from St Margaret’s to their own home, Rosaleen expressed a wish to move to her own home. It would have been determined that Rosaleen needed constant support when leaving the Centre, therefore Rosaleen would have been fearful of leaving on her own and always needed staff with her.



The Corridor in St Margaret’s

Rosaleen lived for 50 years at Sisters of Charity and St. Margaret’s. Her personal space was a bedroom with a wash hand basin. She shared 3 toilets, a bathroom and shower room with 14 on a corridor.

Rosaleen now lives in her own home, has support staff for part of the day; she enjoys time on her own at home and out in the village too. She sometimes makes plans to meet her support staff for coffee rather than them always coming to her house and going out after that.

The service note that Rosaleen was very quiet and reserved when living at St. Margaret’s, she kept to herself and a conversation would have been a greeting, no more than a yes or no or perhaps. Meeting Rosaleen in her own home was so different. She gave a great welcome; she had tea and sat for hours talking about her life, her experiences at home, at Donnybrook and her new life now in her own home.

Rosaleen said she wishes to share her experience with others and to let people know what it is like to have her own home. This conversation between Rosaleen and Breda O’Neill, CEO from St Margarets captures her views,

Rosaleen, what’s it like to have your own home, what does it mean to you?

(Rosaleen is sitting at her own table at home with me as her guest, serving us tea. As we chat Rosaleen tells me what it’s like to be here at home, sighs and says)

“Oh my God, well it’s lovely; after a pause, a short silence she continues, yes it’s lovely to have your own home, your own place; you know, my own place I mean where you can.

come and go, where I can get up when I like, and go out and come home and go to bed when I like, do the things you want to do without some telling you do this or do that or you shouldn't do this or you can't do that; eat this; wait there; get up; look at the time it is, you should be in bed long ago; all that sort of thing, just telling you and you have to do it when they say; that was the way in St. Margaret's. And I have lots of visitors now, not like at St. Margaret's (*she lists many relatives and friends and what they do together*).

You know, I went on holidays to Rome and one of the girls came with me, it was lovely but the cobble stone were awful; ...Oh, the hotel was beautiful, there was even things.....oh, frescos..... on the ceiling in the hotel, I was in the Sistine Chapel in the Vatican too; I liked the Swiss Guards but I didn't like their uniforms – dirty yellow colour, and lovely weather". (*We looked at Rosaleen's photographs of her holiday.*)



About living in St Margaret's Rosaleen recalls:

It was small, very small, I only had my room and I had a lot of things and nowhere to put them; it was a big crowd there, oh yes it was crowded, very crowded, very tight, small space –always a queue for meals, and pushing and people getting annoyed; it was always a hurry but I took my time; people shouted and were angry sometimes; the chapel was quiet and I liked it there and in my room; there was the Infirmary- I was never in there but I went to visit the girls in there sometimes; there were nurses, oh yes, they

would tell you to go here, go there, do this, do that, You know, I was 50 years there, I was 21 when I went there – yes".

The difference between living at St. Margaret's and living here at Woodstock now, what is the big difference for you?

(*Rosaleen taps her finger on the table and thinks about it; then she gently points*)...Oh, it wasn't mine... (*she pauses*).... there, that was never mine; it was never my home and this is my home, that's it, yes, and I decide, of course I decide, like what to eat, when to get up; yes I decide who comes in my front door.

You moved from Donnybrook here, to your own home, tell me about that - “Yes, where did we go? that place, Harvey Normans, Bargaintown, - where else?” *(Cathy, who supports Roslaeen adds IKEA, Homestore & More, Rosaleen agrees)* I picked everything in my favourite colour – blue; I had my bedroom painted blue; my couch is blue; I got blue lampshade, blue light fittings, that blue painting up there, I just said I want it and Cathy said I could, nobody said no.

Rosaleen, what’s it like to have your own home?

I love it, it’s my home, its mine and I can come and go as I please, go to bed when I like and my visitors can come and I can make tea like this, the man came and painted my room blue, my favourite colour, it’s my own isn’t it?

I have loads of mementos that the ladies from St. Margaret’s gave me..., they’re in drawers, I must go through them and take them out; of course I have room now, not like in St. Margaret’s; very little space.



I have a fireplace; I bought that; I wanted it because it’s cosy and we had an open fire at home – in the sitting room and the dining room; Daddy used to dry our hair in front of the fire.

I can help in the kitchen– I peel the vegetables and potatoes; I don’t like the oven, I’m afraid of it; I don’t know why; I think it’s dangerous so I let the girls do that.

I like the garden too; Cathy helped me plant in flowers - John is my handyman; he paints and does the garden too and puts up pictures. I went to a party in the local hall and met Iris – she told me my garden was mess and told me to get John.

Rosaleen, what’s it like to live here, on this street?

It’s nice, I have lovely neighbours I know - Tom from Mayo, John with the dog, that’s John – he painted my bedroom blue and did the garden - Rosemary, she’s lovely, she comes in for tea; Kay gave me a homemade apple tart when I moved in and I never gave back the plate.

You know I go shopping on my own, the shops are just up the road; I know the people in Tesco; I know John the hairdresser in Head Cases – he has tea or coffee and sweets and biscuits left out” *(*Rosaleen gives me a broad smile*) “you know John sent me a card and biscuits when I was in hospital” Cinnamon is my favourite restaurant – the staff are lovely – I really love it and, you know, they know my name; Oh, I have to tell you” *Rosaleen pauses and laughs* “one day I went there for coffee and a desert and I forgot my purse, O Lord, I couldn’t pay them – I said I hope you don’t think I did it on purpose; the girl laughed and she said no and I did pay. I would go down to meet the girls (*staff*) for coffee in Cinnamon. I know the staff in Tesco; they always say hello and chat; when I ask them where anything is they go and get it; they lean over the counter to help me pack my trolley; Oh, one day I bought a big bag of potatoes and the manager, a very nice young man, said where are you going with them; I said I could put them in my trolley; he said no and carried them the whole way down for me, he came all the way home with them, he was very good. Then one evening we were out walking and a crowd of young people met us and one of them said “hello Rosaleen”; he was handsome.

I cross the road at the lights – Mammy used always say practice makes perfect. I got lost one day but I don’t now; I asked somebody where was Woodstock – she told me and I saw the lights to cross the road..... I go to the nail bar to get my nails done sometime”

What colour do you like? “Oh, blue..... I love dark brown eyebrow pencil; I like jewellery; I like to take photographs and I took lots of them... I always liked to take photos.

Rosaleen do you like your own home? Oh my God ...I love it. You ...know, I can come and go, I have my own things, it’s great and all the visitors..... you can visit me again, and the girls come too.

From the Campus to my own Apartment- A Galway Story

This is a short description of a transitional period for a service user in the Brothers of Charity Galway Services who moved to his own apartment from Kilcornan Centre. It is written by his Key worker who worked with Joe in Kilcornan and in his new home in a community setting.

“..Been a service user within the Brothers of Charity since 1983...Up until 18 months ago the service provided for Joe comprised of communal campus based accommodation which was ... secluded and isolated. His contact with the community outside of the campus was facilitated by staff who accompanied Joe at all times. In 2015 Joe moved to within the heart of a local town and is now surrounded by a thriving local community... Joe chose the décor and furnishings for his apartment and helped to paint it. Building on his growing capacity to make decisions and choices for himself, Joe received concrete and emotional support to independently utilise the local community and its amenities... Joe was supported to bring value to the local community when he joined Local Tidy Towns Group....as significantly increased his interactions with the local community.. From a staff point of view, supporting Joe to overcome the negative effects that come with institutionalisation has been significantly challenging. Positive reinforcement and affirmation have greatly enhanced the capacity for staff to help Joe move beyond institutionalised thoughts and behaviours. His many years living in an environment that he had less freedoms still have an influence on Joe. That said, with every new adventure and every new success comes an ever increasing growth of confidence... We are only beginning and looking forward to new challenges and adventures.”

As more personal stories are told and films made to capture the impact of the move to community for individuals and their families, these will be made available for viewing on the Time to Move on webpage and the websites of the National Federation of Voluntary Bodies and individual service providers.

8. Status of Congregated Settings at end of 2017

At the 31st December 2017 there were 2,370 people still living in congregated settings. Below is an analysis of this population and where available a comparison is made against the overall population accessing residential services at the end of 2017. The statistical information on the population accessing all types of residential services has kindly been provided by the Health Research Board who manage the National Disability Databases.

8.1 Profile of Residents in congregated settings on 31/12/2017

The age profile of the residents that remained in congregated settings at the end of 2017 is summarised in Chart 7 below. There has been a shift in the age profile of the population remaining in congregated settings since the *Time to Move on* Report was published. The original report found that half of all residents were in the age range 40-60 years, with a further 20% aged over 60. The 2017 data confirms, similar to the last two annual reports that the population in the congregated settings is ageing. Year on year the proportion of residents in age ranges over 50 years, has increased from 57.9% in 2016 to 60.4% in 2017.

Chart 7: Age profile of residents remaining in congregated setting at end of 2017

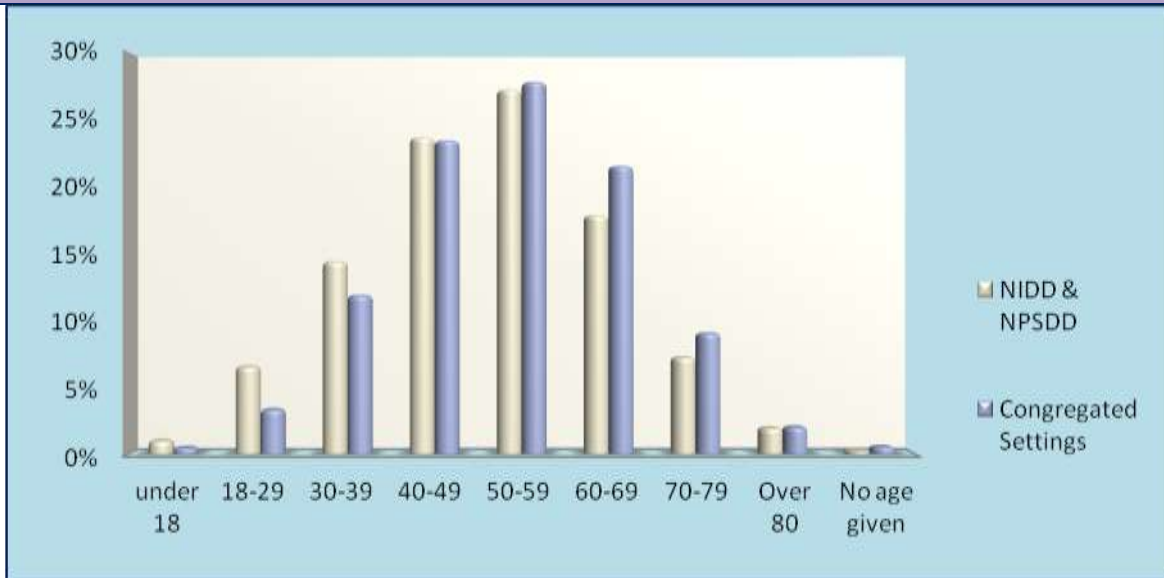


The data is reflecting that similar to people with disabilities in the community, those in congregated settings are living longer.

In Chart 8 below the age profile figures of those in congregated settings is compared to the age profile of all residents accessing a residential service as noted on the National Disability Databases, both at year end 2017. This demonstrates that whilst in both cases

the majority of residents are between 50-59 years of age, the overall age profile of those in the congregated setting is older than in the wider residential sector. On this basis, there will be a higher prevalence of age-related support needs amongst the congregated setting population.

Chart 8: Age profile of residents remaining in congregated setting & all residential settings at end of 2017



In Chart 9 below, the Type and Degree of Disability of the residents that remained in congregated settings at the end of 2017 is given. The population currently living in congregated settings continue to have significant levels of disability with over 1,323 (56%) identified as having a severe or profound level of disability.

Chart 9: Level of disability of people in congregated settings at end of 2017

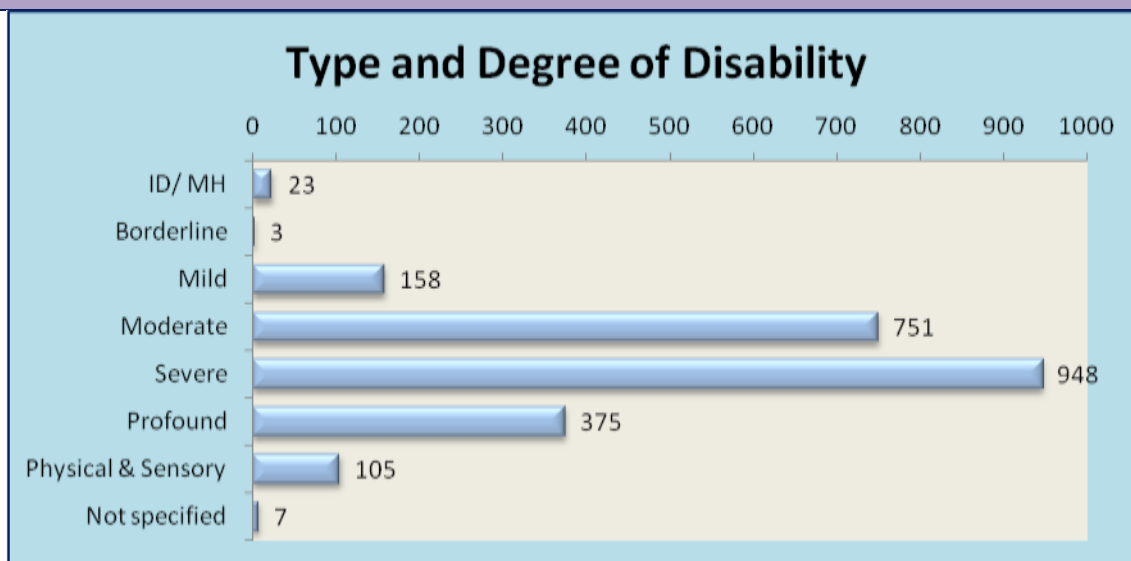
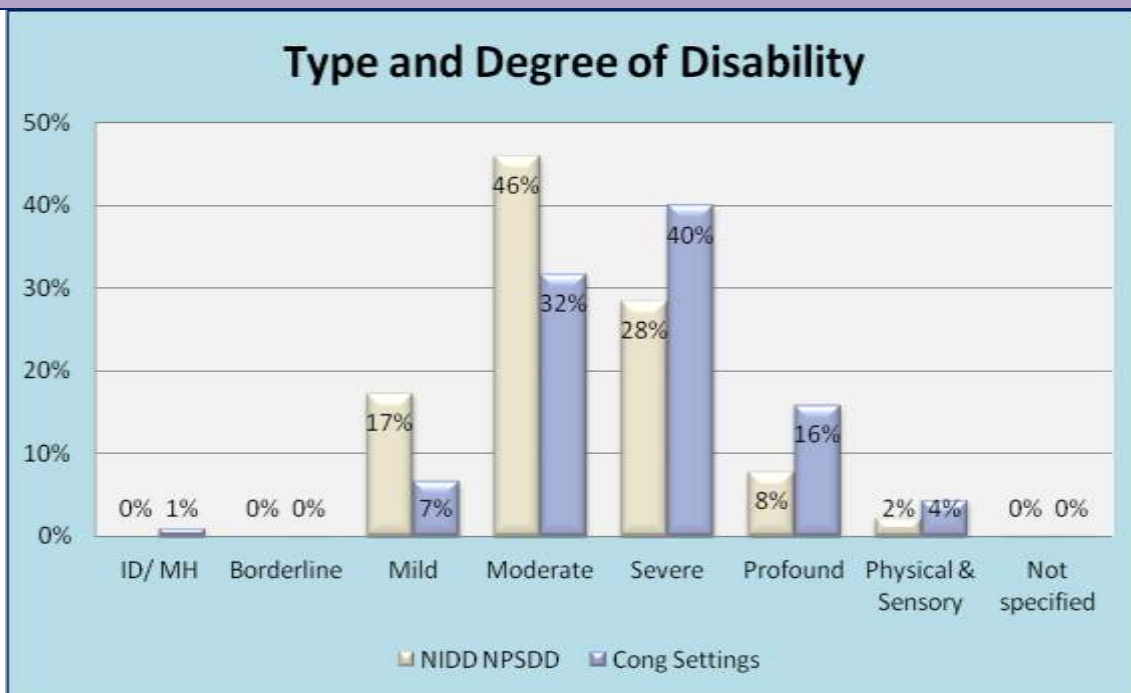


Chart 10 below, shows by percentage the Type and Degree of Disability profile of the population in congregated settings compared to all individuals in receipt of a residential service as recorded on the National Disability Databases in 2017. This indicates that a higher proportion of the resident population in congregated settings (56%) have a severe or profound degree of disability, compared to a prevalence of 34% across all residential services. This suggests that there may be a greater demand for adapted homes and higher support placements as these people move to the community.

However, the data also show that there are already many people with a significant disability living in the community. A total of 2,735 (36%) people are reported as having a severe or profound level of disability, of which 1,323 are in the congregated settings. This means that 1,412 people with a severe or profound disability are currently in community based residential services, which demonstrates that this is appropriate and sustainable for people with significant disabilities.

Chart 10: Type of Disability of people in congregated settings & all residential settings at end of 2017



In addition to the primary disability, Chart 11 outlines the level of support required by people remaining in congregated settings at the end of 2017. Almost 68% (1,610 people) require a high level of support with just under 7% (159 people) requiring intensive support. Of those identified as having high support needs there are 780 people (48.4%) who have a

severe intellectual disability and 351 people (21.8%) have a profound intellectual disability. A further analysis and cross reference of information on those requiring a high level of support shows that 652 of these individuals are aged 50 or under (40.5%), 466 (28.9%) are aged between 50-59 with 485 individuals (30.1%) aged 60 or over. This is an important observation, when we note that the life expectancy for people with disabilities, whilst below that of the general population, has also increased.

Chart 11: Level of support required by people in congregated settings at end of 2017

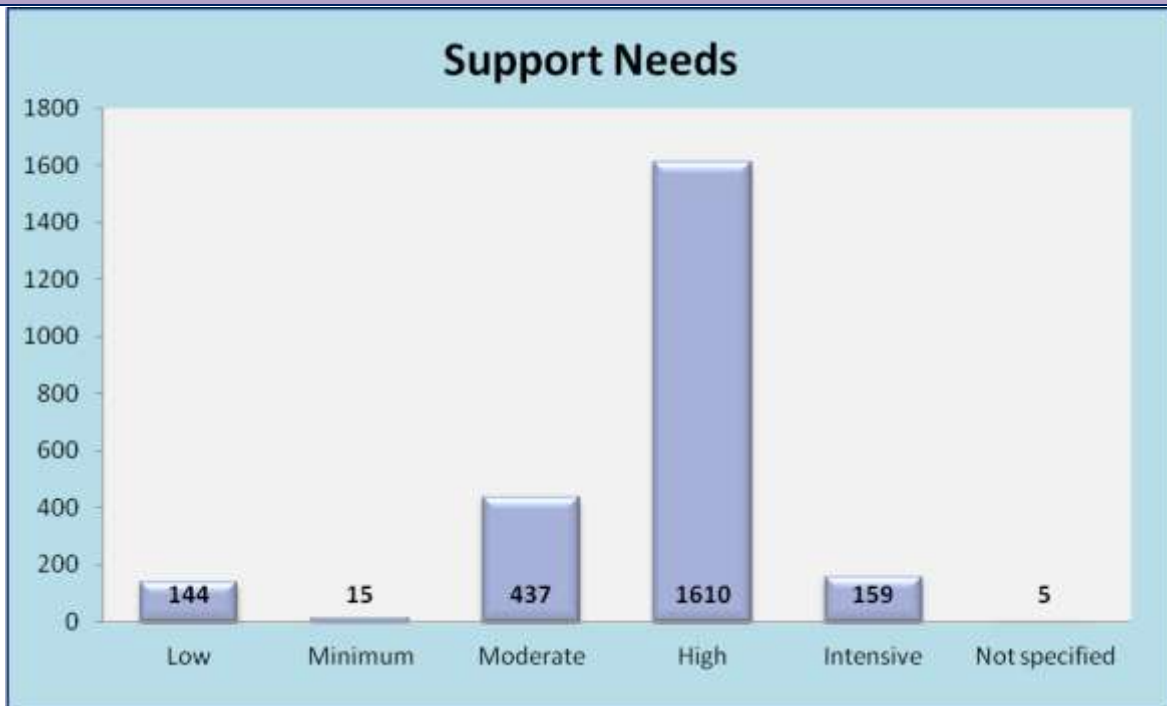
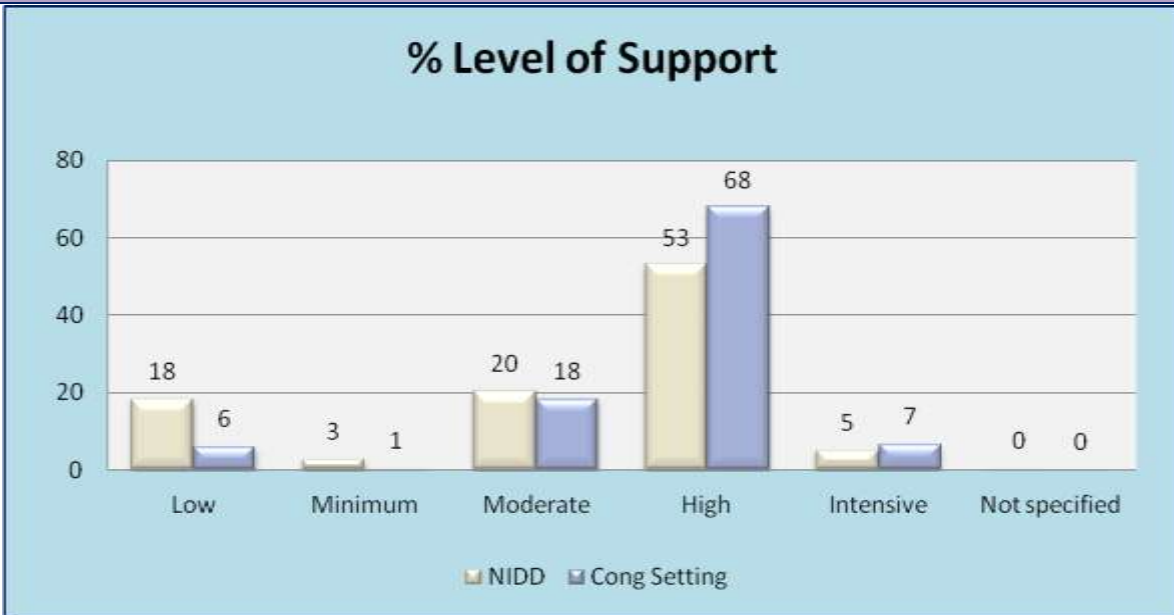


Chart 12 below compares the percentage levels of support needs for residents in congregated settings against all the people in residential services as noted on the National Intellectual Disability Database (NIDD). This shows that the percentage level of support needs recorded is higher amongst those in the congregated settings, where 75% people have high or intensive support needs, compared to 58% (4,381) amongst those registered on the NIDD as receiving residential services. However, an analysis of the data behind the percentages, demonstrates that there is a large numbers of residents with high or intensive support needs, 2,612 people who are currently in community residential services (excluding those in the congregated setting), which upholds the policy position that people with more significant needs can be supported outside of congregated settings.

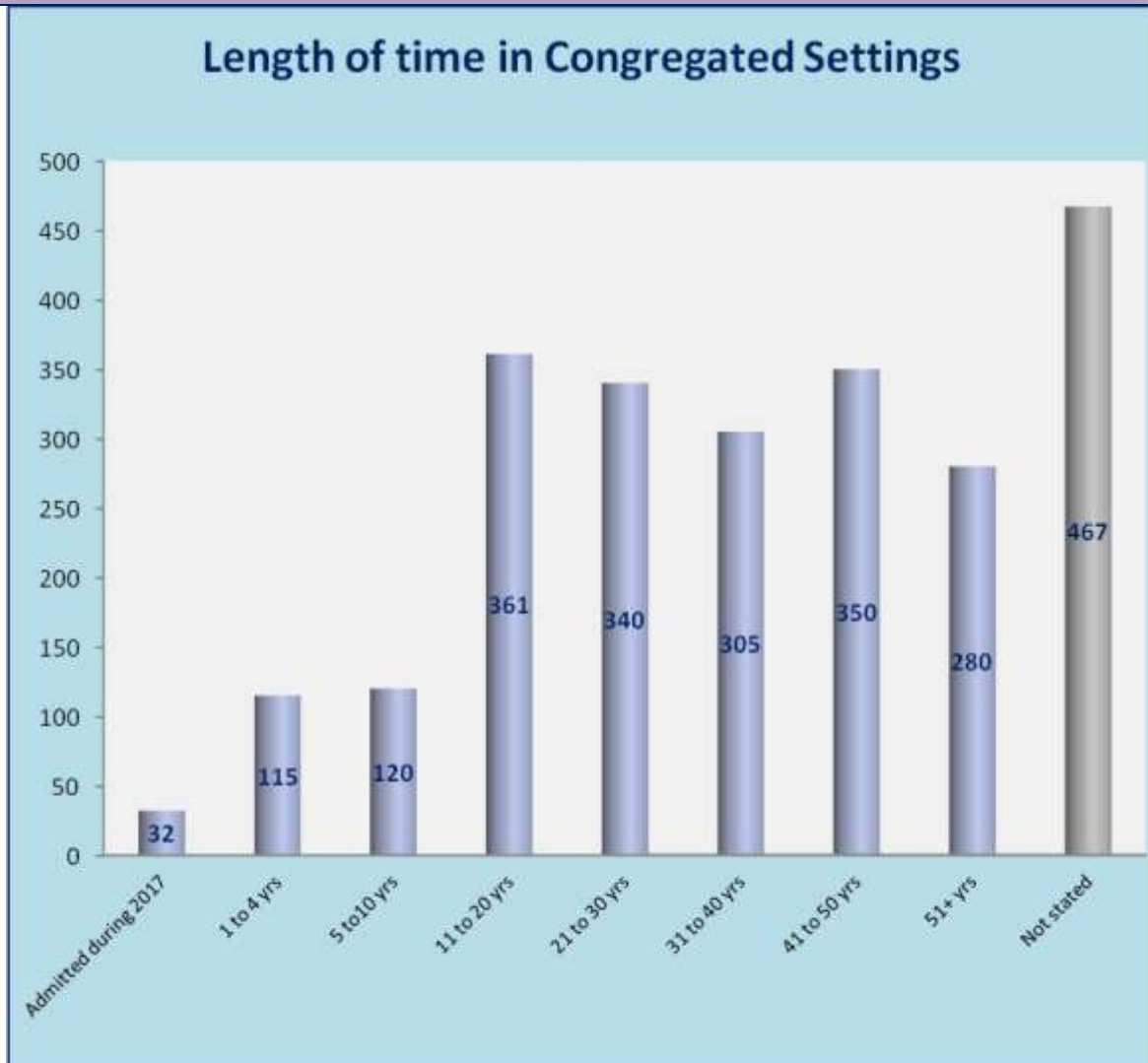
Chart 12: Level of support required by people in congregated settings & all residential settings at end of 2017



Currently, almost 40% of the entire residential population are currently recorded as having low-moderate support needs, and whilst moving residents from the congregated setting to the community will not change the overall profile, it can be anticipated that the upcoming task of supporting people with higher support needs to move to the community may require additional resources, in order to deliver appropriate homes and supports that will enable the individuals to enjoy a good life.

The final table refers to the length of time people having been living in congregated settings. In Chart 13 below, this information is summarised into time bands which shows that 1,275 people (nearly 40%) have now been living in a congregated setting for over 20 years. The average length of time spent living in a congregated setting is now 31 years, amongst the current residents. Information on the length of time individuals have been accessing residential services is not available from the National Disability Databases.

Chart 13: Length of stay in a congregated setting



A set of tables are given in Appendix 2 that provide the following information by CHO area:

- Age profile of residents remaining in congregated settings
- Level of disability of the people that remaining in congregated settings
- Level of support needs of the people that remaining in congregated settings
- Length of stay in congregated setting

9. *Learning and Key Messages to date*

Progress on the implementation of the policy has been slower than originally anticipated in the *Time to Move on* report. The complexity of the process has been a significant factor in this, but it must also be acknowledged, as noted earlier in this report that the changing regulatory and economic environment in which this reform programme has taken place, has had an impact. Nonetheless, by the end of 2017, there has been marked progress and there is now a momentum with many projects being intentionally driven forward by those involved in delivering change, supported by the capital funding programme and the Service Reform Fund.

Success Factors

Reviewing the journey and the progress of the policy across services since 2012 demonstrates that there are common key success factors and activities that are creating solutions and helping drive implementation. These are:

LEADERSHIP:

Clear, supportive and driven leadership

KEEPING IT LOCAL:

Supporting local decision making and local responses

COMMUNICATION:

*Prioritising & supporting
meaningful engagement and communication*

9.1.1 LEADERSHIP: Clear, supportive and driven leadership

Clear and effective leadership are instrumental in bringing about and fully supporting change. Leadership has to be supportive with a focus and commitment on staff development and team building, which ensures the workforce, is supported and enabled to lead and deliver change. There is strong evidence, particularly from the priority sites (supported by the SRF), that dedicating managers or project leaders and a small team of staff to work directly with residents, is often critical in progressing transitions; not least because it demonstrates the leadership vision and commitment to the project.

Importantly, the principle of leadership is not limited to senior managers but includes people at all levels and in all areas of the service. Often referred to as “champions”, the influence and impact of these individuals is often fundamental to bring about long-lasting meaningful changes. The positive impact that these champions have working alongside front line staff, with families, residents and within communities and who lead by example in how they focus on and support the person with a disability cannot be underestimated..

9.1.2 KEEPING IT LOCAL: Supporting local decision making and local responses

A feature of many of the transition projects that have been completed or are making good progress to date, is that at some point they “broke ground”, making a decision to do something new in terms of how the services are organised or provided in order to move forward. Most services will struggle with this at some point, as to “do things differently” and change the status quo, without knowing all the possible implications of a decision, can be unnerving.

Where there is clear leadership with good communication and engagement, staff teams and other key stakeholders can be supported to engage in the process and find and agree solutions that work at the local level, without the need for escalation. The key learning from across the services is that to enable change and keep a project moving forward, managing issues as they arise at a local level is most effective.

It is noteworthy that although the “congregated settings” are referred to collectively, each setting is unique. The identity and culture of each setting has and continues to be influenced by factors that include: the history and background of the service; geographical location; connectivity to and role within the local community; provider organisation; previous model of care and approach to service delivery; current and previous senior management and leadership etc. As a result, there are often nuances to an issue that are site specific, which means that agreeing solutions locally, tends to make them more workable and sustainable once they are aligned to policy, best practise and regulatory requirements.

9.1.3 COMMUNICATION: *Prioritising and supporting meaningful engagement and communication.*

Without exception, the learning from the sites that have progressed decongregation is that communication with stakeholders must be prioritised and be an ongoing process that is actively managed at all stages. To be effective, the communication also has to be appropriate, targeted and time sensitive.

Providers who have learnt by experience specifically warn against the “big town hall meeting” and recommend the “one person and one family at a time” approach. The best approach as to how each service effectively engages and communicates with various stakeholder groups has to be explored and assessed, as often different approaches suit different messages and audiences.

Many services emphasise the benefit of continuous communication and engagement with the resident and their family at every stage of the process. This can include supporting each resident to access advocacy to ensure their voice is heard. Many services speaking from experience agree that each person, along with their friends and family members will have their own understanding, views, ideas and questions. Responding to these questions directly is often most effective and is critical in building trust.

The need for engagement and communication with staff at organisational, team and individual level is also important and must be carefully managed in parallel to processes with all other stakeholders. Services have reported that the most frequent criticism from staff is the belief that the management are not telling them what is planned. Several providers have put in place regular scheduled forums to overcome this, where they provide updates and share information, even if it is only to advise that some decisions are still unclear. This approach has been found to allay fears, build trust and improve collaboration, as over time staff representatives and teams have brought ideas and solutions to the table.

Communication and engagement work can be labour intensive, but services indicate that it does effectively support and enrich the process, resulting in well-planned transitions that will proceed more smoothly. Where there has been an investment in building positive relationships, services are often able to work in collaboration with the key stakeholders to manage any changes in the plan and address issues calmly and collaboratively without derailing the process.

Challenges

As can be expected with a significant change programme of this nature, challenges arise that can negatively impact the rate of progress. Over the years these challenges have primarily been driven by organisational and structural issues and have included: changing organisational culture; resistance from stakeholders; the complexity of reconfiguring staffing arrangements; skill mix; capital and adaptation costs; on-going revenue costs; regulatory pressures; and accommodation challenges (reflecting challenges across the total housing market).

As challenges will inevitably continue to emerge, work will continue at both a national and local level to ensure that solutions are found and shared, which will support the ongoing implementation of the policy.

The challenges and successes year on year are outlined in greater detail in the Annual Progress Reports on the implementation of the policy and are available at <https://www.hse.ie/timetomoveon/>

Key considerations going forward

Through an analysis of the data over the period 2012-2017 and reflecting on the learning from the transitions undertaken to date a number of issues can be highlighted that will need to be carefully considered in terms of the progress of the policy going forward.

“The impact of the capacity of residents to transition and adapt to life in the community”

In many cases providers have reported that they underestimated the capacity of the residents to transition and settle into life in the community. There are examples given where the carefully planned incremental transitions plans were overtaken by a resident’s decision not to return to the congregated setting after their first initial stay in the new home.

Whilst not all examples are this dramatic, commonly providers indicate that the transitions run smoother than anticipated from the perspective of how well the residents cope and adapt. Undoubtedly good forward planning and developing relationships of trust between the residents and their support staff are key to achieving these successes.

There are also examples of difficulties, with some individuals struggling with the change resulting in a step-back, where measures have been taken to slow the pace of a transition or change the approach and plan for and with that person. The learning from a service perspective is to ensure that plans can be flexed to support the acceleration or slowing down of a transition for the benefit of the individual

resident and to avoid being constrained by staffing, housing or organisational restrictions.

“Many of the residents still to move from the congregated settings have been in these settings for an extensive period of their lives”

The data shows that the majority of the residents remaining in congregated setting have lived in these environments for over 20 years. With little experience of living in the community, it is likely that many of these individuals will have a limited frame of reference to enable them to make informed choices. As a result, the transition planning process may take longer as individuals are supported to expand their lived experiences and make choices that enable them to contribute towards and/or direct the development of their own meaningful person centred plan.

In addition to this, potentially a person’s will and preference may change, as they enjoy new experiences over time both before and after their transition. In order to respond to this, greater fluidity may be required in terms of the pace of a plan and the proposed support arrangements post transition.

“The degree of disability and level of support needs of those still to move from congregated settings is greater than those currently in community residential services”

The data indicates that in the main, the population that currently remain in congregated setting have a high degree of disability and support needs. The impact of this is that to support these individuals to move, adaptations may be needed in the new homes and higher levels of support maybe required. In addition to this, the age profile of the residents indicates that changing needs associated with ageing will also need to be considered and planned for in terms of the sustainability of transitions to the community.

For many providers, supporting residents to “age in place” and meet changing needs, is already a challenge in the community based residential services. As more residents transition from the congregated settings, the age profile of people in the community will get older and this will further increase and escalate this challenge.

Interestingly, the data confirms that there are some notable geographical variations in terms of age profile, type and degree of disability and level of support needs. Each CHO Area should consider developing a strategic plan to take account of the particular support needs in their area as part of their planning processes. Appendix 2 provides statistical information on the residents remaining in congregated setting at year end 2017 by CHO Area.

“The need for further enquiry on the supports required post transition”

Currently there are gaps in the information gathered on the support needs of individuals, pre and post transition which could be used to inform service planning. This is a complex area for a number of

reasons. Firstly, service providers currently use an array of different tools to assess the level of support needs, which are not directly comparable. Secondly, other factors that will influence the supports actually put in place for a resident both pre and post transition have to be considered, such as existing staffing structures, skill mix and the support needs of the housemates that a person lives with. Thirdly, any information gathered needs to take account of the impact of the supports for the resident in terms of supporting their person-centred plan and personal outcomes.

The current *Moving In* study being co-ordinated by the NDA is using a combination of assessment tools and approaches to capture this type of information for a number of participants transitioning to community based models of care, both in residential and day services.

Going forward, it will be important that information is captured on the support needs of all residents, the staffing and other support arrangements in place and the impact of this on the residents from a quality of life perspective. This will inform future service planning and development and ensure that models of care are being developed that deliver quality outcomes cost effectively. The Health Research Board's National Ability Support System will provide some useful data as a starting point. The planned introduction of a national standardised assessment tool with a periodic review process, aligned to the National Quality Outcomes Framework for disability services and the Person-Centred Planning Framework will ensure that in the future, the information on support needs can be captured and used effectively to inform service development at all levels in the HSE.

Views from Other Stakeholders

There are many organisations, agencies and groups who are not directly responsible for the delivery or implementation of *Time to Move on*, but are valued stakeholders due to their significant role in working with and supporting the disability sector. These include the Health and Information Authority (HIQA) and the National Disability Authority whose recent commentary on the impact of the policy is noted below.

9.1.4 Health Information & Quality Authority (HIQA)

The positive impact on residents' lives is reflected in the recent Health and Information Authority (HIQA) publication ***Overview of HIQA's regulation of social care and healthcare services in 2017***. This report states that the

“Transition to community-based living had a positive impact on the lives of residents”

The report goes on to reference a particular service and the impact that moving to the community has had for their residents:

“... residents (by St Patrick’s Centre (Kilkenny)) who had previously lived in a restrictive, campus-based environment were now living in a community setting. Residents told the inspector about their first trip to the cinema and a recent holiday experience, experiences that might seem ordinary to many but were very important and meaningful new life experiences for these residents.”

9.1.5 The “Moving In” Study: National Disability Authority

Commissioned under the Transforming Lives Programme the National Disability Authority is co-ordinating a large scale study which is exploring the quality of life outcomes and costs associated with the move to models of disability services which are community based and person centred, called the “Moving In” Study. As part of this study around 150 people living in priority sites for decongregation will be interviewed before and (6-9 months) after they move to the community.

The commentary below has been provided by the National Disability Authority in relation to the progress and findings of the study to date:

While the progress of the decongregation process has been slower than anticipated, a number of moves have taken place, and post-transition interviewing is underway. These interviews have provided some very interesting information, and while we can’t yet assume that these findings will hold true for everyone who moves out of congregated settings to the community, for the most part the outcomes have been positive. Many participants have significant communication and/or cognitive deficits and so interviews were conducted with the support of staff or by proxy.

The majority of those who have transitioned to the community so far have high support needs. Most of the participants lived in congregated settings for many years before their move to the community- many for decades and several for over 50 years. Two of those included in our post-transition interviews were aged 78 and several others were in there 70s.

The post-transition interviews conducted to date provide evidence of significant and at times transformative changes in quality of life following the move to the community. Community integration has greatly increased, family contact is being promoted, challenging behaviours have reduced with a resultant reduction in medication for some participants.

Many of the staff members we encountered on our visits commented on the ease of the transition process. In one residence we were told that before the move staff in the congregated setting commonly expressed the view that the transition would fail and that the residents would return within a week. In fact, staff reported that to their surprise the residents settled in their new home from the first day and the positive changes in their behaviour have exceeded all expectations. A staff member in one house noted that a psychiatrist described the changes in behaviour of one individual as so fundamental that it was like treating two different people. In another house the example of a resident going to a shop and picking a pair of shoes for himself was given to illustrate the improvement in this man's behaviour- previously staff would have considered it unsafe to bring this man shopping.

The participants now live in environments which are quieter, calmer and safer than before. Many have transitioned from locked units and some from dormitory style accommodation. The noise level is lower because there are fewer people and because in many cases challenging behaviours have reduced. They now have their own bedrooms and live in a home with usually 3 other persons. Bedrooms provide residents with privacy - a space of their own where they can rest, display family photographs and other personal mementoes.

Although some of those who have moved to the community are physically frail many are robust and healthy. These participants now have more opportunities to engage in physical exercise. We heard accounts of a range of physical activities such as hill walking, horse-riding, long walks on beaches and swimming. Staff attribute better sleep patterns and reduced restlessness and challenging behaviours to the increased physical activity.

Since their move to the community some participants continue to attend day centres within the campus where they previously lived. Others only return to the campus on rare occasions or not at all. The move to the community has promoted social integration as participants now access community based services and activities to a far greater extent than in the past. The community activities reported include going to local pubs and coffee shops, attending GAA matches, hill-walking with a local group, as well as sporting activities such as swimming and horse-riding.

In many instances staff report increased family contact since the moves have taken place. Families find it easier to visit in the less crowded, quieter, more homely surroundings. Staff

have actively sought to strengthen family bonds. This can be especially difficult when people have spent decades in institutional care and when parents are deceased, but in one case the occasion of the participant's 60th birthday was used to re-establish contact with family members and has resulted in now ongoing contact with siblings. This type of reconnection has been seen in a number of cases in the study.

Overall, the results to date indicate very positive improvements in quality of life for those who have made the move to the community. The results indicate that on-going study of outcomes for those who transition from congregated settings is merited.

10. The Critical Next Steps

The 2016 *Programme for a Partnership Government* confirmed an on-going commitment to delivering the policy and identified a revised target of achieving a one-third reduction of the numbers remaining in congregated settings by the year 2021. The Government has also ratified the United Nations (UN) Convention on the Rights of Persons with Disabilities. Article 19(a) states that people with disabilities should be able to choose where, and with whom, they live. Together these two actions reaffirm ongoing support for the policy at government level, which is vital for a project of this nature which will continue to need creative thinking, clear and vocal support and resources.

For the next year, the HSE 2018 *National Service Plan* (NSP) continues to prioritise the implementation of the *Time to Move on* policy. Specific actions include supporting a further 170 individuals to move to the community and continuing to realign the workforce to deliver a person-centred social care model with a specific focus on achieving this in congregated settings. The inclusion of defined actions and targets in the NSP ensures that a focus will be kept on progressing the policy.

It is important that we continue to support learning from the experiences of those involved in decongregation, by gathering and sharing information on the transition process, the new emerging models of service and the quality outcomes for people with disabilities both in the short and longer term. The findings from the *Moving In* study along with a number of other research projects and studies currently underway, will contribute to this learning.

As the momentum of the project is gathering pace, attention has to be paid to the overall configuration of disability services and supports to ensure they will be sustainable and support the long-term meaningful integration of people with a disability into the community that will enable them to enjoy an ordinary life. Key considerations for community services in this regard will be: capacity-building in local communities; equitable access to mainstream supports and services; and the evolution of disability services to enable people to enjoy a meaningful day and age in place. There will be a focus on ensuring the appropriate and equitable implementation of the policy for individuals with significant specialist residential support needs, including age-related support needs.

Work will continue on an ongoing basis to ensure that: existing resources are being effectively deployed; resource gaps are identified; bids for any additional resources are well

informed; the learning and experience gained is used effectively to improve outcomes and drive cost effectiveness; and challenges continue to be pre-empted and addressed. Attention will also be needed as further progress is made, to manage the particular issues that will arise with the planned closure of residential services on the larger campus's which will include funding issues, disposal of lands and assets, workforce planning, addressing pockets of resistance and the arrangements for other services that are currently campus-based.

It also has to be noted that the full enactment of the Assisted Decision Making legislation, the planned review of the Wards of Court by the Decision Support Service and the drafting of new legislation on the Deprivation of Liberty are all developments on the horizon that will impact disability residential services as well as many other services and aspects of society. Whilst these are not imminent, the HSE and service providers need to consider the impact of these changes and begin preparations to support the implementation of this legislation. Communicating and engaging with the key stakeholders, including the frontline staff, families and residents will be a priority. Ensuring each resident is fully supported to exercise their capacity for decision making will create new challenges in service delivery and impact the relationship between the resident, family, staff and service provider from a legal perspective.

Going forward, the HSE Disability Services, the *Time to Move on* group and the Project Team must continue working to support the implementation of the policy. Engaging with service providers, HSE colleagues in the CHO teams and other groups of stakeholders will be key to achieving this.

Appendix 1: Statistical Information CHO Transitions 2012-2017

Age of Residents Transitioned from Congregated Settings 2012-2017

Age	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
	2	0	0	0	0	0	0	0	5	7	1.1%
18-29	6	0	2	6	4	1	3	4	4	30	4.5%
30-39	8	7	6	16	12	4	10	20	1	84	12.7%
40-49	15	9	12	18	22	15	11	39	0	141	21.3%
50-59	5	12	9	25	24	17	13	62	9	176	26.6%
60-69	3	9	4	26	5	27	2	32	8	116	17.5%
70-79	0	3	0	20	2	11	2	8	1	47	7.1%
80 Plus	0	0	0	6	0	6	0	2	0	14	2.1%
Not Known	2	0	0	0	0	3	2	3	36	46	7.0%
	41	40	33	117	69	84	43	170	64	661	100.0%

Degree of Disability of Residents Transitioned from Congregated Settings 2012-2017

Degree of Disability	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Borderline	0	0	0	0	0	0	0	0	1	1	0.2%
Mild	1	3	0	17	0	16	6	12	2	57	8.6%
Moderate	18	10	12	38	10	17	25	51	32	213	32.2%
Severe	14	18	17	46	38	12	11	83	19	258	39.0%
Profound	2	3	4	11	20	5	1	19	2	67	10.1%
Physical & Sensory	3	6	0	5	1	10	0	1	0	26	3.9%
Dual Diagnosis	1	0	0	0	0	16	0	4	1	22	3.3%
Not Known	2	0	0	0	0	8	0	0	7	17	2.6%
	41	40	33	117	69	84	43	170	64	661	100.0%

Level of Support to Residents Transitioned from Congregated Settings 2012-2017

Level of Support	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Low	7	3	0	10	2	12	3	8	9	54	8.2%
Minimum	0	0	0	2	0	4	0	2	0	8	1.2%
Moderate	4	9	1	37	7	32	10	25	13	138	20.9%
High	28	24	15	60	55	21	25	131	26	385	58.2%
Intensive	0	4	6	8	5	8	4	4	8	47	7.1%
Not Known	2	0	11	0	0	7	1	0	8	29	4.4%
	41	40	33	117	69	84	43	170	64	661	100.0%

Length of Stay of Residents who transitioned from Congregated Settings 2012-2017

Length of Stay	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Less than 1	4	0	1	3	4	1	0	2	5	20	3.0%
1-4 yrs	1	3	0	7	1	5	3	0	8	28	4.2%
5-10 yrs	2	1	3	8	6	12	2	4	5	43	6.5%
11-20 yrs	8	5	3	20	10	24	9	10	5	94	14.2%
21-30 yrs	4	14	3	35	8	20	9	60	4	157	23.8%
31-40 yrs	12	12	4	19	24	12	3	35	2	123	18.6%
41-50 yrs	3	0	6	10	12	3	8	32	2	76	11.5%
50 yrs plus	0	3	1	3	3	2	0	15	5	32	4.8%
Not known	7	2	12	12	1	5	9	12	28	88	13.3%
	41	40	33	117	69	84	43	170	64	661	100.0%

Appendix 2: Statistical Information CHO Residents Remaining 2017

Age of Residents Remaining in Congregated Settings year end 2017

Age	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	HO 8	CHO 9	Total	%
0-18	0	0	1	0	5	3	2	0	0	11	0.5%
18-29	8	2	5	22	10	5	9	0	18	79	3.3%
30-39	21	10	40	87	22	18	48	5	30	281	11.9%
40-49	54	25	59	188	39	27	71	25	67	555	23.4%
50-59	55	24	67	179	25	25	120	42	122	659	27.8%
60-69	32	29	37	101	27	24	110	29	121	510	21.5%
70-79	14	17	14	34	7	16	44	2	66	214	9.0%
80 Plus	2	5	2	11	1	1	6	1	19	48	2.0%
Not Known	1	0	1	1	1	0	6	0	3	13	0.5%
	187	112	226	623	137	119	416	104	446	2370	100.0%

Degree of Disability of Residents Remaining in Congregated Settings year end 2017

Degree of Disability	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Borderline	0	0	0	1	0	0	0	0	2	3	0.1%
Mild	2	4	4	67	3	21	14	2	41	158	6.7%
Moderate	59	35	60	204	24	40	143	16	170	751	31.7%
Severe	86	55	119	222	58	18	133	62	195	948	40.0%
Profound	19	2	26	100	51	11	121	24	21	375	15.8%
Physical & Sensory	20	16	15	26	1	27	0	0	0	105	4.4%
Dual Diagnosis	1	0	0	2	0	2	5	0	13	23	1.0%
Not Known	0	0	2	1	0	0	0	0	4	7	0.3%
	187	112	226	623	137	119	416	104	446	2370	100.0%

Level of Support of Residents Remaining in Congregated Settings year end 2017

Level of Support	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Low	4	4	5	77	1	11	5	0	37	144	6.1%
Minimum	2	0	5	5	0	2	0	0	1	15	0.6%
Moderate	33	75	14	136	5	41	63	4	66	437	18.4%
High	142	31	168	366	116	60	319	96	312	1610	67.9%
Intensive	6	2	34	39	15	5	29	4	25	159	6.7%
Not Known	0	0	0	0	0	0	0	0	5	5	0.2%
	187	112	226	623	137	119	416	104	446	2370	100.0%

Length of Stay of Residents Remaining in Congregated Settings year end 2017

Length of Stay	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO 6	CHO 7	CHO 8	CHO 9	Total	%
Less than 1	3	0	3	14	4	0	3	1	4	32	1.4%
1-4 yrs	13	8	12	26	13	1	10	4	28	115	4.9%
5-10 yrs	14	7	7	29	12	17	11	0	23	120	5.1%
11-20 yrs	19	24	47	58	8	59	62	10	74	361	15.2%
21-30 yrs	26	60	56	65	21	20	47	9	36	340	14.3%
31-40 yrs	42	11	60	66	32	12	35	19	28	305	12.9%
41-50 yrs	40	2	35	74	36	4	65	35	59	350	14.8%
50 yrs plus	20	0	6	16	0	5	61	26	146	280	11.8%
Over 80 Years	0	0	0	0	0	0	0	0	0	0	0.0%
Not known	10	0	0	275	11	1	122	0	48	467	19.7%
	187	112	226	623	137	119	416	104	446	2370	100.0%

Report Dated: September 2018

Suzanne Moloney, National Disability Specialist - Time to Move on Project Lead

Email: timetomoveon@hse.ie